Washington State Department of Health

Human Prion Disease

(Rare Disease of Public Health Significance)

Disease:

LHJ Use **ID** _____

Please enter the case in PHIMS as a Rare Disease of Public Health Significance and send/fax this form to DOH Communicable Disease Epidemiology.

County

Investigator _____
Phone/email _____
_____

Investigation complete date
___/___/___

REPORT SOURCE

Initial report date ___/___/___

Investigation start date ___/___/___

Reporter (check all that apply)
☐ NPDPSC lab ☐ Hospital
☐ Public health agency ☐ Health Care Provider
☐ Other_____

OK to talk to surviving relative?
☐ Yes ☐ No ☐ Don't know

Reporter name _____Reporter phone _____

HCP1 name _____HCP1 phone _____

HCP2 name _____HCP2 phone _____

Notes: _____

PATIENT INFORMATION

Name (last, first) _____

Address _____ ☐ Homeless

City/State/Zip _____

Next of kin: Name _____

Next of kin: Phone _____

☐ Spouse ☐ Parent ☐ Child ☐ Sibling ☐ Legal guardian

☐ Other relative _____ ☐ Other _____

Primary occupation _____Employer/worksite _____

Birth date ___/___/___ Age _____

Gender ☐ F ☐ M ☐ Other ☐ Unk

Ethnicity ☐ Hispanic or Latino
☐ Not Hispanic or Latino ☐ Unk

Race (check all that apply)
☐ Amer Ind/AK Native ☐ Asian
☐ Native HI/other PI ☐ Black/Afr Amer
☐ White ☐ Other ☐ Unk

CLINICAL INFORMATION

Onset date (mm/yy) ___/___ ☐ Derived Diagnosis date ___/___/___ Illness duration _____ days/months/years

Clinical Findings

First symptom(s) _____
_____
_____

Y	N	DK	NA	
☐	☐	☐	☐	Neurodegenerative disease
☐	☐	☐	☐	Progressive dementia
☐	☐	☐	☐	Cerebellar signs (e.g., poor coordination/ataxia)
☐	☐	☐	☐	Visual abnormality
☐	☐	☐	☐	Myoclonus
☐	☐	☐	☐	Pyramidal signs (e.g., hyperreflexia, spasticity)
☐	☐	☐	☐	Chorea
☐	☐	☐	☐	Dystonia
☐	☐	☐	☐	Other extrapyramidal signs (e.g., rigidity, tremor, shuffling gait)
☐	☐	☐	☐	Akinetic mutism
☐	☐	☐	☐	Progressive neuropsychiatric disorder
☐	☐	☐	☐	Early psychiatric symptom(s) (anxiety, apathy, delusions, depression, and/or withdrawal)
☐	☐	☐	☐	Persistent painful sensory symptom(s) (frank pain and/or dysesthesia)

Notes on clinical symptoms _____
_____
_____
_____

Clinical Findings

Y	N	DK	NA	
☐	☐	☐	☐	EEG performed Date___/___/___
☐	☐	☐	☐	EEG with periodic sharp wave complexes

EEG result_____
_____

☐	☐	☐	☐	MRI performed Date___/___/___
☐	☐	☐	☐	Diffusion weighted MRI

MRI result_____
_____

☐ ☐ ☐ ☐ Indication of an alternative, non-prion disease diagnosis (i.e., subarachnoid hemorrhage, encephalitis, stroke with acute infarction, multi-infarct dementia with acute infarction, brain neoplasm, paraneoplastic neurological disorder)

Hospitalization

Y	N	DK	NA	
☐	☐	☐	☐	Hospitalized for this illness

Hospital name/City _____
Admit date ___/___/___ Discharge date ___/___/___

Y	N	DK		
☐	☐	☐	Died from illness	Date of death ___/___/___
☐	☐	☐	Autopsy	Age at death _____
				County of death _____

Answers are: Yes, No, Unknown to case, Not asked /Not answered

Case Name: _____

Laboratory

Y N DK NA

☐ ☐ ☐ ☐ 14-3-3 protein test performed on CSF
Test date ___/___/___
☐ Elevated ☐ Ambiguous ☐ Not elevated

☐ ☐ ☐ ☐ Brain biopsy performed
Date of procedure___/___/___
Laboratory where tissue sent:
☐ Nat Prion Disease Path Surv Center (NPDPSC)
☐ Other laboratory:_____

Laboratory

Y N DK NA

☐ ☐ ☐ ☐ Brain autopsy performed
Date of autopsy___/___/___
Laboratory where tissue sent:
☐ Nat Prion Disease Path Surv Center (NPDPSC)
☐ Other laboratory:_____

☐ ☐ ☐ ☐ Neuropathologic confirmation

☐ ☐ ☐ ☐ Confirmation of protease-resistant prion protein by immunohistochemistry or Western blot

☐ ☐ ☐ ☐ Presence of scrapie-associated fibrils

POSSIBLE SOURCES

Predisposing Factors

Y N DK NA

☐ ☐ ☐ ☐ Family history of prion disease in a 1º relative

☐ ☐ ☐ ☐ Prion gene mutation

Exposures

Y N DK NA **Has the patient ever…**

☐ ☐ ☐ ☐ Spent 3 months or more in the U.K. since 1980?

☐ ☐ ☐ ☐ Lived outside the United States
Country_____ Specific Months/Year_____
Country_____ Specific Months/Year_____
Country_____ Specific Months/Year_____

Y N DK NA **Has the patient ever…**

☐ ☐ ☐ ☐ Received human-derived pituitary hormones (e.g., growth hormone)
Dates ___/___/___ to ___/___/___

☐ ☐ ☐ ☐ Received a dura mater or corneal allograft
Date ___/___/___

☐ ☐ ☐ ☐ Had neurosurgery (on brain, spinal cord or eyes)
Date ___/___/___
Anatomic Site_____
Hospital name/city _____

CASE CLASSIFICATION

Sporadic CJD: ☐ Definite ☐ Probable ☐ Possible

Iatrogenic CJD: ☐ Definite ☐ Probable

Familial CJD: ☐ Definite ☐ Probable

Variant CJD: ☐ Definite ☐ Probable ☐ Possible

☐ Other prion disease _____

☐ Prion disease unlikely

☐ Cannot be determined/provider report only

Source(s) of Patient History

☐ Chart review ☐ Provider interview ☐ Patient interview

☐ Relative/friend interview Name _____ Relationship _____

NOTES

PUBLIC HEALTH ISSUES

Y N DK NA

☐ ☐ ☐ ☐ Case donated organs or tissues
Date___/___/___
Facility _____
Organs/tissues donated_____

☐ ☐ ☐ ☐ Case underwent neurosurgery or eye surgery
Date___/___/___
Facility _____
Procedure_____

PUBLIC HEALTH ACTIONS

Y N DK NA

☐ ☐ ☐ ☐ Blood/tissue/organ program notified
Date___/___/___

☐ ☐ ☐ ☐ Surgical facility notified
Date___/___/___

☐ ☐ ☐ ☐ Report sent to CDC
Date___/___/___

Answers are: Yes, No, Unknown to case, Not asked /Not answered